

Delivery of cancer care in rural India: Experiences of establishing a rural comprehensive cancer care facility

INTRODUCTION

With the increase in number of cancer cases in India, the number of Tertiary Cancer Centers with excellent infrastructure and trained oncologists is also increasing in urban India. However the same is not true about rural India. This is reflected in the fact that, though the incidence of cancer in rural India is nearly half of that of urban India, the mortality rates are double. This needs to change, especially with the fact that 70% of Indian population is rural. This commentary discusses how cancer care can be effectively and economically delivered in rural India, referring to the experience the author had while establishing a comprehensive cancer center in rural India.

CANCER DEMOGRAPHICS IN INDIA

The number of cancer patients in India is going to double in next 30 years. This increase is not as much as because of true increase in the incidence of cancer, but mainly because of increase in our population; improvement in facilities leading to more patients being diagnosed to have cancer; and also because the median lifespan of the Indian population has increased from 45 years at independence to 66 years in 2010. Compared to developed nations, the cases of cancer detected in India are low, but mortality rate is high.^[1] Most (68%) patients with cancer die of their disease in India as compared to only 33% in USA.^[1,2] The incidence of cancer in rural India is increasing alarmingly because of changing lifestyles and urbanization of rural India in addition to all the reasons mentioned above. At the same time, there are hardly any cancer facilities in rural India.

THE PARODY OF CANCER CARE IN INDIA

Patients from villages and smaller cities have to go to major cities for cancer therapy. Because of financial

constraints and cultural barriers, these patients present late to the Tertiary Cancer Centers (TCCs). Most TCCs are overcrowded, and because of decreased manpower and limited infrastructure, there are further delays in treatment. Also because of our male dominated society, fewer females are brought to the tertiary centers for treatment and this is reflected in the higher male:female ratios in most hospital-based registries. Furthermore, in cities, the families face cultural shock with no place to stay and difficulties in commuting. In addition, they also face the loss of job and daily wages. This leads to refusal, abandonment or noncompliance of treatment. Many go back once their limited finances are exhausted. Some are lost because of infections and malnutrition related toxicities. This leads to the poor outcomes in rural patients with cancer. The parody of cancer care in India is that the early (curable) cancers are made incurable by inappropriate treatment given locally by nononcologists without using principles of oncology; at the same time, patients with advanced, metastatic (incurable cancers) — patients who may only need palliative care — are referred to TCCs. This leads to inappropriate use of the limited, precious resources. All this will hopefully change if more rural comprehensive cancer centers (RCCCs) are developed. Barshi has already set an example in this regard.

ACCESS TO CANCER CARE IN RURAL AREAS

Nearly 70% of Indian population lives in rural India. However, nearly 95% of cancer care facilities are in urban India. Thus, though the incidence of cancer in rural India is nearly half of that of urban India, the mortality rates are double.^[3] If cancer care has to be improved, more centers have to be developed in the smaller cities and in rural India.

There are few facilities disseminating cancer awareness, early detection and early diagnosis in rural regions. Even the biopsies or the blood samples are sent to cities and the reports take weeks to come back. By the time, the patient can arrange the logistics to go to cities for treatment, it causes further delays in treatment and advancement of the disease. All this leads to the vicious cycle: Because these patients come with advanced disease, the outcomes are poor; and because of poor outcomes, other rural patients are not motivated to take proper treatment on time. If this

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10.4103/0971-5851.158848

vicious cycle is to be broken, treatment has to be organized for the rural patients at their doorsteps, in their familiar environment.

Another reason why patients flock to the urban cancer centers is because support is available there. Cancer care is becoming expensive day by day, and in India where most of the healthcare is self-funded, most of the patients do out-of-pocket payments for cancer care. It is beyond the reach of most rural patients to take cancer treatment on their own. Ironically, most of the societal help given by trusts or nongovernmental organizations—be it financial or logistic, is available to patients taking treatment in TCCs in cities. Even government help like Health Ministers Fund, Rajiv Gandhi Arogya Yojna, etc., is approved mainly for TCCs. Thus, patients are forced to go to cities for treatment. This flow can be stopped if all such help is also made available in rural centers.

SUPPORT NEEDED TO DEVELOP RURAL COMPREHENSIVE CANCER CENTERS

The development of RCCC would also help urban TCCs take better care of patients, since their patient load will decrease if rural patients are treated locally itself. The urban TCCs — public and private — could each adopt one or more such rural center and help it develop into a RCCC. The team from the TCC (comprising onco-surgeon, radiation oncologist, medical oncologist, and onco-pathologist) could visit the rural center at regular intervals and also arrange to train local doctors at the TCC. With the availability of Skype, Webinar, telemedicine facilities, interval consultations can be carried out when needed. With the availability of courier services, pathology slides/blood samples from RCCCs can also be sent to TCCs to save time and reports E-mailed. Finally, students of all oncology specialties who train at TCC should be rotated through RCCC to understand and learn optimum utilization of basic infrastructure offering the best outcome in the absence of expensive, Hi-tech Intervention. This kind of interaction will instill the importance of novelty and creativity in devising and implementing cancer care.

It would be very important to link all these rural cancer units across India through the National Cancer Grid (NCG). This will allow the exchange of expertise between centers and to create a ready network of centers for collaboration research in cancer.^[4] As projected, the real success of NCG will be apparent when overall cancer outcomes in India improve considerably, parallel with patients getting the highest quality cancer care at their door step.^[4]

These rural cancer centers should also have a registry attached to it since estimating the cancer burden not only

helps us to formulate policies, but also to gear-up for further management strategies.^[5] The types of cancers seen at each centers may be unique. The commonest cancer recorded in Barshi rural registry is cervical as opposed to head and neck cancers in the Ratnagiri rural registry (interestingly the M:F ratio at Ratnagiri was 45:55 as compared to 55:45 at TMH, thus supporting the fact that less females are brought to TCCs for treatment). The registry should cover not only cancer cases, but should be extended to other common noncommunicable diseases with more or less similar etiological functions like cardiovascular disease and diabetes and stroke under the National Center for Disease Informatics and Research.^[5] The Ministry of Health and Family Welfare, Government of India has formulated a National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular disease, and Stroke after integrating the National Cancer Care Program (NCCP) with other noncommunicable diseases.^[5]

ESTABLISHMENT OF A MODEL RURAL COMPREHENSIVE CANCER CENTER

The Tata Memorial Centre (TMC), one of the largest comprehensive cancer center in Asian subcontinent, through DAE grant, commissioned a model rural cancer control program titled “TMC — Rural Outreach Program” (TMCROP) in Ratnagiri and Sindhudurg districts (total population approximately 3 million) of the Maharashtra State in Western India in 2002.^[6,7] BKL Walawalkar Hospital (BKLWH), a charitable hospital, located in Dervan, Chiplun (Maharashtra) was selected as the base hospital within the region for implementing the TMCROP project because of the basic infrastructure available there. With the help of TMC, this hospital has since been conducting a model cancer program in the Ratnagiri and Sindhudurg districts of Maharashtra for last 13 years. The TMCROP had specific goals viz:

1. Creating health awareness about all cancers in general and specifically about oral, breast and cervical cancers;
2. Screening for precursors/early stages of cervix, breast and oral cancer among women, and oral cancer among men; and
3. Treatment of cases detected in these screening camps.

With the help of BKLWH, TMC has developed cheaper ways of not only early cancer detection, but also cost-effective ways for treatment of common cancers.

All aspects of cancer care including diagnosis, surgery, chemotherapy, and later even radiotherapy was taken care of at BKLWH itself. This significantly increased the overall compliance for treatment completion. The existing pathologist, physician and surgeons at the BKLWH were trained at TMC for a suitable period to enable them to

undertake cancer treatment and management. Oncology consultants (surgical oncology, radiation oncology, medical oncology, pathology) from TMC also visit the base hospital on a monthly basis. This has helped to develop BKLWH as a RCCC. At present, the 4th year residents of various oncology specialties who train at TCC are rotated through BKLWH.

Though the financial burden per cancer patient in India is one of the lowest reported (\$641 as compared to \$86,758 in USA),^[1] even this is out of reach of many patients from this region since they earn <\$75/month. One of the most important challenges in India is not only to find cure for cancer, but to develop affordable cancer care. Thus, it would be very important to give stress on cancer prevention (including tobacco control), developing cost-effective screening techniques for early detection, developing indigenous radiotherapy equipment, use of generic drugs, and also going after drug repurposing rather than drug discovery.^[8] In addition, there should be initiation of research between modern medicine and traditional therapies (like Ayurveda, Homeopathy, Unani) which are widely used in the country. All this is being done at BKLWH, making it a model RCCC. All the treatment for patients on the TMCROP project was delivered free through funding from DAE grant and services provided by BKLWH.

Most basic oncosurgeries are done at the BKLWH itself. The occasional patient requiring complex surgery is referred to TMH. Less intensive surgeries are compensated by giving neo-adjuvant chemotherapy, peri-operative therapies, and/or maintenance therapies, specially developed at BKLWH, without affecting the outcomes and maybe even improving the outcomes.^[9,10]

Since in the rural centers, many patients present with advanced disease and many others need palliative care, radiation therapy would be required to complete the effective therapy. Thus, it is very important that each of these rural cancer centers is equipped with Radiotherapy facilities. At the BKLWH, Bhabhatron II, the refined version of the very Indian cobalt machine and confirmed to be better than other state of art machines of its class, was installed in 2009 and is functioning well ever since. Recently, Siddharth, the LINAC jointly developed by CSIR-CSIO Chandigarh and SAMEER Mumbai, is being installed at BKLWH.

Most of the published literature consists of therapies developed in affluent countries. These are then used in developing countries since they are considered “standard of care.” However, these protocols do not take into consideration the locally existing infrastructure, available supportive care, as well as local socioeconomic realities.

There is an acute need to develop affordable, effective treatment for these rural patients with cancer with treatment delivered locally. All the chemotherapy protocols used at BKLWH are developed using drugs listed on the WHO essential drug list. Many metronomic scheduling of anti-cancer therapies protocols were developed for patients with recurrent disease, which were found to be affordable and effective.^[8] These were later also used in newly diagnosed cancer patients with advanced disease at presentation.^[8-10] Not only the cost of drugs is low, but these protocols can be delivered with minimal infrastructure: Only an occasional patient required blood or platelet support, and in most patients even laboratory investigations such as complete blood count, liver function test, renal function test was done once in 2-3 months. Using this pilot data, some of these metronomic therapies are now being investigated in phase II/III trials at TMH.

Thus, over the years TMC has helped BKLWH evolve into a model RCCC which offers optimal cancer care that is cost-effective. This also includes rural cancer registry which was started in 2009 to gauge the magnitude, type of cancer problem and document trends in incidence and mortality, the two important yardsticks in NCCP. The main focus is on creating cancer awareness and prevention. Simple cost-effective methods have been developed for early detection which can be executed by paramedics.

We all want to win the war over cancer. However, wars cannot be won with generals (the TCCs) alone. We also need the foot soldiers (the rural cancer centers) to be on the same page. The mission of the RCCC at Walawalkar hospital is to be a shining example of the fusion of science and humanity and to serve as a catalyst for the NCCP. TMC-ROP could become a role model for other TCCs to develop ROPs, which will greatly increase the cancer care facilities for the vast rural population of our country.

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How to cite this article: Banavali SD. Delivery of cancer care in rural India: Experiences of establishing a rural comprehensive cancer care facility. *Indian J Med Paediatr Oncol* 2015;36:128-31.
Source of Support: Nil. **Conflict of Interest:** None declared.

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